

Guidelines for Using Community Voice



Community Voice is an empowering volunteer opportunity for the CF community to share their experiences, perspectives, and knowledge. Members impact research, care, and programs, shaping the future for the CF community through participation in projects like surveys, focus group, and committee work.

In return for receiving input from Community Voice, those who use the group share the results and impact of their project with the members.

To get started, review our [Community Voice User Guide](#) and contact communityvoice@cff.org.

What services does the Community Voice team offer?

- Access to feedback and insights from more than 1500 people with CF and their immediate family members, including parents, spouses, and siblings
- In-depth consultation for your project, including:
 - High-level summaries of previous data collected from the CF community on your topic
 - The most effective way to collect feedback from the community
 - Best practices on how to recruit community members into your work
- Guidance on survey development
- Comprehensive data analysis

What is expected of users of Community Voice?

For your project to qualify, it must meet these criteria:

- Fit the mission of the CF Foundation and aim to have a positive impact on the CF Community
- Are sensitive to the community's needs and concerns
- Are sensitive and considerate of the diversity within CF community
- Gather new information that is meaningful to the community
- Contain a description of how the results will be used and the plan to share results with the community
 - We understand that publishing or institutional review board protocol timelines may determine what updates can be shared with the community and when. Our team is happy to work with you to clarify these issues.

How do I cite & acknowledge Community Voice in my work?

To recognize the work of CF community members, the Community Voice team requests that users of this group acknowledge its members in published manuscripts, abstracts, posters, and presentations. Please refer to the [Community Voice User Guide](#).